DOCUMENT RESUME

ED 196 247 EC 131 397

AUTHOR Smith, Bert Kruger; Culler, Ralph E., III
TITLE Avondale House: An Innovative Approach for Disturbed Children and Their Families.
INSTITUTION Texas Univ., Austin. Hogg Foundation for Mental Health.
PUB DATE 80
NOTE 20p.
AVAILABLE FROM Hogg Foundation for Mental Health, P.O. Box 7998, University Station, Austin, TX 78712 ($0.30; quantity discounts)

EDRS PRICE MF01 Plus Postage. PC Not Available from EDRS.
DESCRIPTORS *Autism; Daily Living Skills; *Family Programs; *Family Relationship; Program Descriptions; Psychological Needs; *Respite Care

ABSTRACT

The needs of families of autistic children are discussed and a program designed to prevent unnecessary institutionalization by providing comprehensive services and reducing the stress in the child's family is described. Parents participate through voluntary, program related, and support activities. The family services include respite care and parent and sibling training. Child oriented services focus on community living skills. (CL)

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AVONDALE HOUSE

An Innovative Approach for Disturbed Children And Their Families

by
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INTRODUCTION

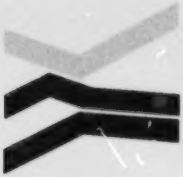
Beyond the quickly averted gaze his handsome face, now mutely eloquent, whispers, "I am the autistic, the Gordian knot. Loosen me and let fall the veil that yet surrounds the mind and brain of man." The baseline of human mentation, he is the child seemingly born psychotic, who, frozen in an endless epoch of being that does not distinguish animate from inanimate, knows not even that he is alone.

Receiving less than he contributes to science, the interpretation of his demeanor ranging from idiotic to extraterrestrial, he is a living agony within his family who can never adapt him to themselves and the world nor the world and themselves to him. Families are knowledgeable about breakthroughs on scientific fronts, but their own breakthrough consists of their first weekend alone since his infancy.

Such family respite is now increasingly possible through the combined efforts of the concerned community, an adaptive device as old as families themselves. This gathering is one of self-help, mutual support, and realistic cooperative planning in the face of a tenacious and otherwise devastating problem.

Though numerous groups address the needs of the autistic child and his family through professional services, few provide the anchorage that the autistic community has now developed within itself at Avondale House. Read further and listen for the answering voice of the creative human spirit at work.

James S. Robinson, Director
Houston Child Guidance Center



THE NEED

"America is a child-centered country."

"Americans love their children."

"To be a child is to be attractive, healthy, nourished, and slightly spoiled. To have dolls that walk and wet and eat and play or to have trains and fire engines with lights and motors and luminous paint. To be able to have and do almost anything one wants."

These statements, frequently made, widely believed, may, on close observation, be found to be less than accurate. While it is true that many children are catered to and indulged and although a large number of youngsters are richly nourished both physically and emotionally, it is also true that many young people exist minimally. Only in dramas or books – or real life – does one view the negative of the beautiful picture described above. There on the dark side of the wonder lies reality. The reality of a child who is abused. Or neglected. Or severely disturbed.

How many seriously disturbed young people exist in this country? Reliable estimates are scarce, and criteria for judging vary greatly.

No one can give exact figures for the numbers of such children. It is thought that about two percent of all children born are eventually diagnosed in that fashion.

Of all the serious disturbances, the most devastating and baffling is autism. What causes autism? What is the villian?

Is it genetics? There is indication that a genetic weakness may impinge on some environmental situation to cause this special problem. Research has pointed to such probability.

Or – is it biochemical? There are those who think biochemistry plays a major role in autism. Studies have shown that overactivity of the sopamine system or over- or underactivity of the thyroid or extra amounts of lead in the blood may exist in the autistic child.

Environmental? Most experts think not. Many of the children who are later categorized as autistic have shown bizarre or unusual symptoms almost from birth.

Even the recognition of autism as a discrete disability is somewhat recent. Dr. Leo Kanner, a Johns Hopkins University psychiatrist, published in 1943 a classic article about 11 children suffering from what he called early infantile autism. He chose the name from the seeming "aloneness" manifested by these young people. The one characteristic which they all share is their noninvolvement with other persons. They are youngsters "apart."

The Children

Almost every child is born of a dream. Mothers carry within them a reality of the growing infant as well as the hope that this child will be warm, loving, intelligent, and obedient. The discomfort, expense, fatigue will be offset, it is believed, by the joy and the sense of fulfillment.

But the gentle dream turns into nightmare for parents of children who do not "fit the norm." For parents of children with minor disabilities the disappointment may be transitory; for those fathers and mothers of infants with serious problems, the reality can be nearly immobilizing. The ultimate pain often comes from having a child who is diagnosed as autistic – a child who is unresponsive and seemingly unaware.

A child who may regard his parents as inanimate objects.

Who may scream with pain, the source of which is not obvious.

Who may withdraw from all contact with others, isolated within the uncertain boundaries of his own emotions.

A young person who may spend hours spinning wheels, turning tops, watching lights.

Whose day must be so structured that no object in his room can be moved so much as an inch or no food altered in any way.

Who may seem to be deaf or retarded or hyperactive.

These children differ in the way they manifest their illness. However, they share the sense of isolation, fear of people, and feelings of panic. They have been described in this way:

"Some of them living in homes of comfort are terrified of starving; others are so afraid of poisoning that they will starve themselves. Some have wild delusions of grandeur to compensate for their feelings of utter despair. Some have fears of persecution, as real to them as if they were in a Nazi prison camp suffering all the tortures of that nightmare.

"There are boys and girls so compulsive about cleanliness that they will not eat food which has been touched by anyone else or handle a book which someone else has held. Others go through ritualistic motions of cleaning each part of their bodies. There are children who are compulsive eaters, others who vomit everything they swallow, and some who refuse food altogether. Some children hide their bodies from everyone's eyes, others masturbate openly. There are others whose body functions are uncontrolled.

"They have often been so afraid of the world, characterized by their rooms or homes, that they have spent their time huddled in a corner, covered by a blanket, or they have retreated to a bed like an infant who finds security within the framework of his crib. These children, like the infants they once were, are often afraid of falling. They are also afraid of going to bed at night because they cannot tolerate the threat of being fully alone with their own fearful feeling. Often these children have no sense of time or space or place. They live in limbo, creatures spiritually homeless.

"They may perceive themselves in a number of disturbed ways, or they may not perceive themselves at all. Some of them will not look into a mirror; they do not know that a face will be

reflected. Many of them have such distorted ideas of their own bodies that they cannot step off a curb or around a corner without holding on to something solid. They lose contact with their extremities. They are insecure, unsure of what they are or who they are, or even where they are.

"The faces of many of these children are sorrowful, classic pictures of desolation. These youngsters can often be observed in grief-bent postures, unresponsive to the living world around them. They find their salvation in the only way they know – by retreating. They often 'melt' into the wall or into a chair. They deny people and regard them as they do a chair, a stove, or a table. They learn that 'things' are real and dependable; they feel that human beings are often unreal and unreliable. They 'turn off' pain, as 'normal' people sometimes do under very painful emotional conditions (for instance, one might 'tune out' the unpleasantries of a dentist's chair by imagining oneself on the beach in Hawaii).

"They cannot trust, these frightened children. They must hide whatever they want to keep. They will hoard or put away food, pin treasures in their pockets, place gifts inside their pillows. They will share with no one.

"They are truly children without a country, for they have no sense of belonging to anyone or anything. They feel they may be deserted at any moment. Any change makes them experience the desolation of abandonment."[1]

The Parents

In the past parents of severely disturbed children had to cope not only with the baffling and heartbreaking problems of their

[1]Smith, Bert Kruger. *No Language But a Cry*. Boston: Beacon Press 1964, pp. 4, 5, 6, 9, 10.

children but with the dispassionate attitude of professionals. The mothers were characterized as being cold and unloving; the fathers as unresponsive or absent. Never mind the fact that these parents spent hours every day, seven days a week, with a child who was demanding, distracting, and exhausting. Disregard the money spent on trying to find some physician or some program to offer viable suggestions for treatment. Fail to consider the lost family cohesiveness and gentle relationship while members are involved in attempts to deal with this "different" child.

One professional confessed to his own faulty perception as follows. Dictating a letter about his studies, he said, "We try to make parents full partners in our efforts." His secretary turned to him and asked, "Isn't it presumptuous to state that *we* make parents full partners?"

This authority has related his renewed insights as he recognized the truth of that statement. Parents are and must be the most concerned individuals regarding the children and their needs. It is the parents who have brought the child into life; it is they who are responsible for his development and his growth.

Parents are unable to resign their charge. They cannot plead "burn out" and go away. They cannot decide that they have had enough.

They are the lifeline and the support system. They are the chief area of defense in regard to their children. Increasingly, good therapists are enlisting parents in helping disturbed young people.

Family Needs

Vital concern for the needs of children and adolescents was expressed by members of the President's Commission on Mental Health. One Task Force reported as follows: "Yet no matter how many preventive measures our society adopts, up to and

including full employment and guaranteed income policies, there will always be children who require special help . . . Therefore, we recommend a network of psychiatric, pediatric, counseling, special education, and occupational training services . . . Treatment must address the cause of the illness and include counseling for parents and other adults in the child's life."

The report continues, " . . . In contrast to the trend toward deinstitutionalization of adults, there remains a scarcity of residential resources for children and adolescents. Good residential facilities, specializing in the treatment of autistic, psychotic, retarded, multihandicapped, and suicidal children and adolescents are desperately needed."[2]

Despite the fact that progress has been made concerning the needs of young people with problems, many thousands of school-aged children are dropouts or pushouts from the public school. They are like puzzle pieces which do not fit into any mold. Often parents are uncertain and distraught; schools relinquish responsibility; communities fail to see the need; and many young people drift from boredom to delinquency to adult crime or mental illness.

Prevention, in terms of the young population, is of extreme importance. The members of the President's Commission viewed the need and wrote as follows:

> As the Commission traveled throughout America, we saw and heard about too many children and adolescents who suffered from neglect, indifference, and abuse, and for whom appropriate mental health care was inadequate or nonexistent. Too many American children grow to adulthood with mental disabilities which could have been addressed more effectively earlier in their lives through appropriate prenatal, infant, and early child development care programs. Troubled children and adolescents, particularly if they are from racial minorities, are too often placed in foster

[2] *Task Panel Reports Submitted to The President's Commission on Mental Health* Volume III. Washington, D.C.: Superintendent of Documents, U.S. Government Printing Office, pp. 6, 7, 1978.

homes, special schools, mental and correctional institutions without adequate prior evaluation or subsequent follow-up. Good residential facilities specializing in the treatment of special problems are in short supply . . .

Services that reflect the unique needs of children and adolescents are frequently unavailable. Our existing mental health services system contains too few mental health professionals and other personnel trained to meet the special needs of children and adolescents. Even when identified, children's needs are too often isolated into distinct categories, each to be addressed separately by a different specialist. Shuttling children from service to service, each with its own label, adds to their confusion, increases their despair, and sets the pattern for adult disability.[3]

Chronically, severely disturbed children have long frustrated both their parents and concerned professionals. However, resignation has been replaced by positive action in some programs. Several years ago in Houston a small nucleus of dedicated, enlightened parents came together to plan an innovative method of care. Their efforts – their *successes* – are described in this pamphlet.

[3]*Report to the President from The President's Commission on Mental Health* Volume I. Washington, D.C.: Superintendent of Documents, U.S. Government Printing Office, pp. 6, 7. 1978.

A MODEL FOR MEETING THE NEED

In 1976, several families in the Houston area united to cope with a problem they all shared: lack of alternative resources for their seriously disabled children. At that time, only two choices existed - to place the child in an institution such as a state hospital or to suffer the social isolation and family disruption which develop when a seriously disturbed child is cared for at home. Working together, this "cooperative" of families rented a two-story house, hired a program director and formed the Texas Treatment Center for Autism. The agency they created offers a variety of services to severely disturbed children and their families in the Houston-Galveston area. In 1979 the Treatment Center acquired a much larger house on Avondale Street and became known as Avondale House.

During its first 30 months of operation, Avondale House has helped to meet the needs of 85 families with disturbed children in the Houston-Galveston area. The population served is a heterogeneous one with most of the children being at least mildly retarded, but varying greatly in actual diagnosis. Approximately 40% are autistic while the remainder suffer from psychosis, brain dysfunction, and other disabilities. The ages of the children range from six to late teens and males outnumber females by about two to one. The children are referred primarily by parents or the schools, but some 12% come from other professionals or agencies.

Philosophy

Its philosophy of service and treatment is a unique characteristic of Avondale House. The primary goal of the center's program is to prevent the unnecessary institutionalization of dis-

turbed children by making it possible for them to remain in their natural or surrogate homes. The program aims at providing a comprehensive spectrum of services and support relationships which are responsive to both short-term and long-term needs of these children.

A complementary objective is to reduce the stress in the child's family and maintain family integrity. The disabled child is viewed not as an isolated problem but in the context of his or her nuclear and extended family. The family, on the other hand, is seen as requiring support services in order to function adequately with a disturbed member. It is the emphasis on the family as the client and the involvement of the parents and siblings in the program which makes Avondale's approach unique. Parents are active in the program in three ways: 1) *program direction*; 2) *volunteer effort*; and 3) *support activities*.

Program Direction The Avondale House program was designed and implemented by concerned parents to meet their families' needs for alternative care for one of its members. Continued parental involvement in the decisions regarding the program is effected by having parent representation on the Board of Directors. Through this process, choices about the type of care available, fee schedules, and other decisions receive direct input from the actual consumers. Because only five children can be served in residence at a given time, the selection of those children is important. That responsibility rests ultimately with the Board of Directors with, of course, recommendations from the staff. Additional youngsters are served on a day-care or after-school basis.

Volunteer Effort Offering residential treatment and respite services can be a very expensive undertaking. The costs of maintaining individuals in 24-hour care can run upwards of $100 per

day; and when this all is passed directly to the consumer, it is prohibitively expensive. In order to offer service at a reasonable rate, Avondale House has arranged for much of the routine work to be done by the parents. To ensure equal participation, the parents are "billed" for volunteer hours commensurate with the hours of service given to their children which can be "paid" by working at the center at night or on weekends. Membership on the Board of Directors counts towards the volunteer hours required.

Support Activities Generally, a family's role, if any, in a treatment program for children is that of "patient." This limited role stems from a common belief that the parents themselves are somehow responsible for their child's disturbance and need treatment (i.e., therapy) themselves. But, while it is true that many disturbed children come from families with problems, " . . . programs that offer parents only a single vehicle for involvement (clinical treatment) may overlook the numerous other possibilities for growth and change available to them."[4]

Avondale House offers such options. Parents never receive treatment at the center and, of course, they are not "blamed" for the condition of the child. Rather, each family participates in activities designed to give them information about a disturbed child's condition and to allow parents the support of others with similar problems. These activities include covered dish dinners, support group meetings, and Saturday work sessions during which parents and siblings are able to mingle with others facing the same demands and problems.

[4]Whittaker, James K., *Caring for Troubled Children*. San Francisco: Jossey-Bass Publishers, 1979, p. 138.

Service

If there is a single theme in the service program of Avondale House, it is pragmatism. At this time there is no "cure" for autism, no miracle treatment which will make an autistic child normal. Also, few of these children will outgrow their disturbance. It is the realization that their clients will probably have a longtime handicap that molds the service – not treatment – program at Avondale House.

While the clients for the center are the families and not the children alone, different services within the program usually have a direct impact on either the child or the parents and in some cases the siblings. Services which enhance the ability of the family to cope with its disturbed child will, of course, have a beneficial effect on the child.

Since autism and other disabilities seen at Avondale House are considered lifelong conditions, the services directed at the children are aimed at development of skills and abilities they will need to cope with situations they will face as adults. The program giving them this training is called Community Living Skills and is ongoing 24 hours a day at the center. When the children get up in the morning, they learn to brush their teeth, wash, dress, and make their beds. As simple as these activities sound, many of the children come to the center without the ability to do any of these things for themselves. At breakfast, and for all the day's meals, the children learn to assist in the preparation and service of the food as well as in the cleanup afterwards.

During outings to the zoo, stores, movies and other public places, the youngsters learn what is appropriate behavior and what is not acceptable, an area in which they often are unskilled. Families often will refrain from taking the child into public places because of posssible embarrassment. Staff members, unlike the parents, feel neither guilt nor shame at the unexpected actions of the young people and thus are able to help them learn social skills.

Other training is given in sex-education, recreation, socialization, pre-vocational and vocational areas. As a child becomes more skilled, he or she is able to spend increasing periods of time at home, thus releasing some of the center's precious bed space.

Services for the families are of two types: 1) those that help the parents and siblings to cope with the presence of the disturbed family member and 2) respite care which enables them to "get away" for a while from the responsibility of caring for the child. It is the combination of support services and respite care which makes this a viable alternative to institutionalization.

Support services for the family include a wide array of resources such as after school and weekend day care, babysitting, homemaker service, family counseling, big brother/big sister programs, transportation to and from the center and on an emergency basis, guardianship and trust information, and legal aid. In addition, parents receive both formal and informal training, information and counseling about their child at the center and through the group experiences available there.

The various respite opportunities available at Avondale House are as important as the support services. The center can provide respite care for an evening ("parents' night out") or for longer periods in those cases where a child cannot be maintained at home. By offering a wide range of respite options, Avondale House makes optimal use of the five beds it has available and is able to serve adequately as many as forty families during the year.

The center thus serves in the capacity of extended family, offering a kind of life support which may make an unbearable situation possible to endure. Families learn case management of the child and share ideas of life management for the child.

Sit around a lunch table with some of the mothers. Ask them what life has been like since they gave birth to these children with severe and lasting problems. You will be surprised first at

the candor of these women who have fought their way through many kinds of medical, scholastic, and treatment problems before they found their way to Avondale House. They are pioneers who have cleared new paths, and they show strength developed from their efforts.

One attractive blue-eyed mother may talk of a firstborn daughter, pretty, petite – and different from other infants. She slept for minutes instead of hours like other newborns. She did not learn to smile, to reach out, to cuddle. However, she seemed precocious, beginning to talk at eight months.

She started walking – and ceased talking. She hit her head. She screamed without apparent reason. She would go into a tantrum if someone so much as turned an alphabet block to another letter or moved a toy to a different place.

When a second child, another daughter, was born, the differences between the two girls became increasingly noticeable. And the long search began for someone who would know what to do for this strange firstborn. The hunt took the family to pediatricians, to centers for retarded children, and to other organizations.

Even when the family learned the name "autism" and put the little girl into a program, they were not invited in to discuss and learn techniques for many months. However, at Avondale House they are part of the treatment team. They understand behavior modification and means of working with their daughter.

Their marriage, shaky during some of the difficult years, has become strengthened with the healing help of staff and of other parents. The younger sister, able to talk with other family members, can accept this "different" member of the family without shame or apology to others.

For another mother, the marriage came undone during the years of trying to find help for her daughter, a second child. This little girl seemed to be cuddly and warm at first. Then, at about 18 months she was in noisy distress. Screaming, pinching, grabbing, she pierced the air for hours at a time. She picked at her

ears until they bled, bit the stairs and banisters in the house, broke through walls. Her terrors were expressed at unexpected times – at the sight and sound of various commercials on television, at being in a car which was backing out.

The mother is convinced that if she had been able to obtain some relief during the time her child was acting out, the marriage might not have dissolved. To her the center offers an alternative to insanity.

Still other parents talk of children who are unaware of the appropriateness or inappropriateness of behavior, who at the age of 12 cannot dress themselves, who masturbate in public, and who amuse themselves by playing in the dirt.

WHAT THIS MODEL DEMONSTRATES

Avondale House exemplifies a move from the strict, cold professionalism manifest in the recent past to a philosophy of personal caring and attention on the part of everyone who comes in contact with the disturbed child.

Techniques of modern medicine can help to save many infants who in earlier years might have died at birth. Quite a few of these infants retrieved are those who may have serious problems, physically or emotionally. Care and habilitation of such damaged children become very costly, and the resources available for such treatment are limited.

The implementation of PL 94-142, federal legislation providing for education for all handicapped children, has served to bring into focus and awareness many children who in earlier years would have been "hidden away" or institutionalized without accurate diagnosis or treatment. However, early experiences with implementation of the law indicate that striking, imaginative, and innovative ways of serving the population of needy children must be found.

Therefore, developing less costly methods of working with mentally ill children becomes an imperative. Enlisting parents and other community volunteers (including many of the able elderly) is a viable method for approaching the problem of serving these youngsters. In addition, the infusion of community and family support systems can be therapeutic in itself, helping to erase the "differences" which many of these children have felt in their relationships with other people.

Can the autistic child become a "normal" adult with proper care and services? This question lies on the tongue of every parent of such a young person.

The answer cannot be made definitively. Depending on the severity of the disability and the intensity and success of treat-

ment, the child may grow up to be a person needing supervision on a 24-hour basis. Or, he might go on to live in society, holding a job, and perhaps even marrying. Most adult autistic persons remain "different" from other people. They are generally "loners," non-communicators, and seemingly cold. However, some of them learn enough social skills to be able to interact with other people. Even though regarded as eccentric, such adults nevertheless can function on their own.

Promise for the future may lie in replication of programs like Avondale House. The pragmatic method, modest cost, and innovative philosophy of service to both children and their families make such an approach an effective model for those concerned with seriously disturbed children.